

### Definition and Types

Spina Bifida is a type of neural tube defect where the spine does not form properly within the first month of pregnancy. Two types of Spina Bifida are Meningocele, and Myelomeningocele.

- Meningocele, the least common form, occurs when the covering for the spinal cord protrudes through the back.
- Myelomeningocele, the most severe form, occurs when the actual spinal cord protrudes through the back.<sup>1</sup>

Children with Spina Bifida may have a variety of health problems. Some children may need braces, crutches, or wheelchairs since they may not be able to move portions of the lower body. A lack of bowel and bladder control is common in children with Spina Bifida. A build up of fluid in the brain also is a common complication associated with this birth defect.<sup>2</sup>

### ABDMP Data Collection

The ABDMP staff reviews hospital records, birth, and death certificates in order to identify potential cases. If potential cases are identified, the staff review the medical records to confirm that the child has a reportable birth defect. Once confirmed, information from the abstract is entered into the Arizona Birth Defects Monitoring Program.<sup>3</sup>

### United States Estimates

There are approximately 70,000 people in the United States living with Spina Bifida.<sup>4</sup> The societal and economic lifetime cost associated with caring for a child that has been diagnosed with Spina Bifida is between \$500,000 and \$1 million.<sup>5</sup>

In 1992, the Centers for Disease Control and Prevention (CDC) recommended that women of childbearing age consume 400 micrograms of synthetic folic acid daily. Then in 1997-1998, the Food and Drug Administration required the addition of folate to enriched cereal-grain products. The United States prevalence rate for Spina Bifida between 1999 and 2001 was 3.68 cases per 100,000 live births. Fortification was associated with a 34% drop in spina bifida rates in the U.S.<sup>4,6</sup>

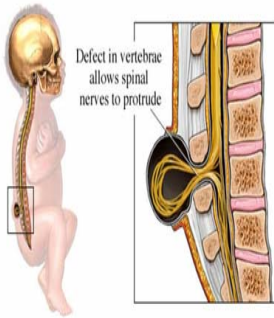
### Spina Bifida in Arizona

Approximately 34 babies are born each year in Arizona with Spina Bifida. Between October 1998 and December 2003, the average rate of Spina Bifida in Arizona decreased (following the folic acid fortification of many cereal foods). The rate of Spina Bifida during the pre-folic acid fortification period was 4.95 per 10,000 live births. The rate post-folic acid fortification was 4.16 per 10,000 live births. The prevalence ratio (post-fortification prevalence/pre-fortification prevalence) is 0.84 (95% CI: 0.70-1.01). This 16% reduction in the occurrence of spina bifida falls somewhat short of the 34% decrease seen nationally.

The rate for Whites (non-Hisp) is 3.10 per 10,000 live births. The rate for Native Americans is 5.13 (95% CI: 2.99-8.22) per 10,000 live births an elevated rate compared to Whites (non-Hisp). The rate for Hispanics is 4.97 (95% CI: 3.99-5.95) per 10,000 live births. This rate is elevated and statistically significant compared to Whites (non-Hisp) (Figure 4).

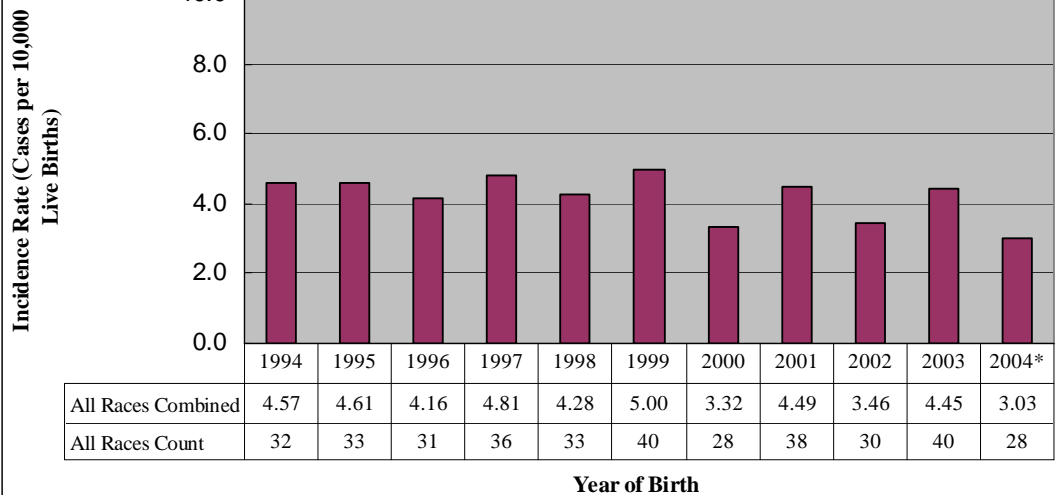
## Spina Bifida in Arizona

Figure 1: The average rate of Spina Bifida for all races in Arizona between 1994 and 2004 is 4.20 cases per 10,000 live births.



A clinical presentation of Spina Bifida.<sup>7</sup>

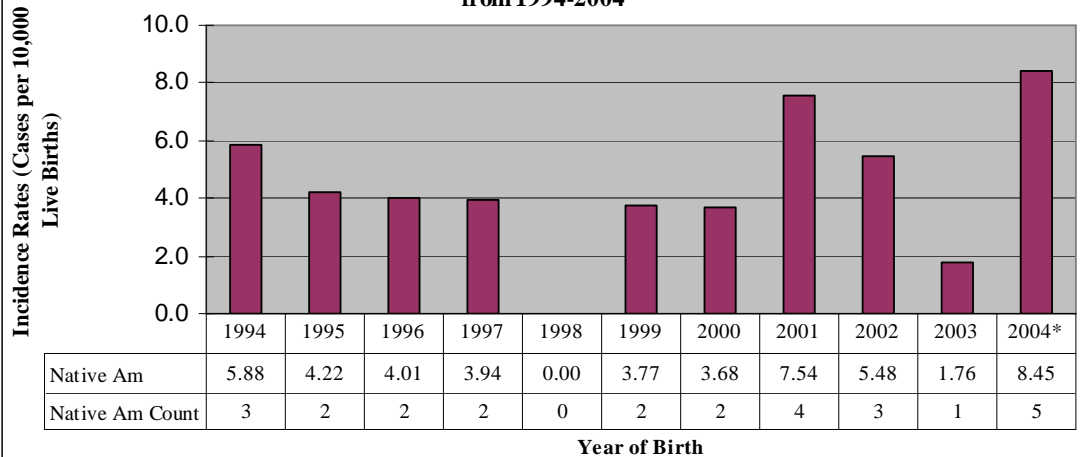
**Figure 1: Rate (live and still born) of Spina Bifida for All Races Combined from 1994-2004\***



Source: Arizona Department of Health Services, Arizona Birth Defects Monitoring Program, 1994-2004  
\* 2004 data not yet complete

Figure 2: The average rate of Spina Bifida in the Native American population between 1994 and 2004 is 4.52 per 10,000 live births. The small count of cases makes the yearly rates unstable.

**Figure 2: Rate (live and still born) of Spina Bifida for Native Americans from 1994-2004\***



Source: Arizona Department of Health Services, Arizona Birth Defects Monitoring Program, 1994-2004  
\* 2004 data not yet complete

*Rates of Spina Bifida in Arizona are higher among Native Americans and Hispanics.*

## Facts about Spina Bifida, 1994-2004, Arizona

Figure 3: The average rate of Spina Bifida in the Hispanic population between 1994 and 2004 is 4.95 per 10,000 live births with no clear temporal trend.



Baby with Spina Bifida.<sup>8</sup>

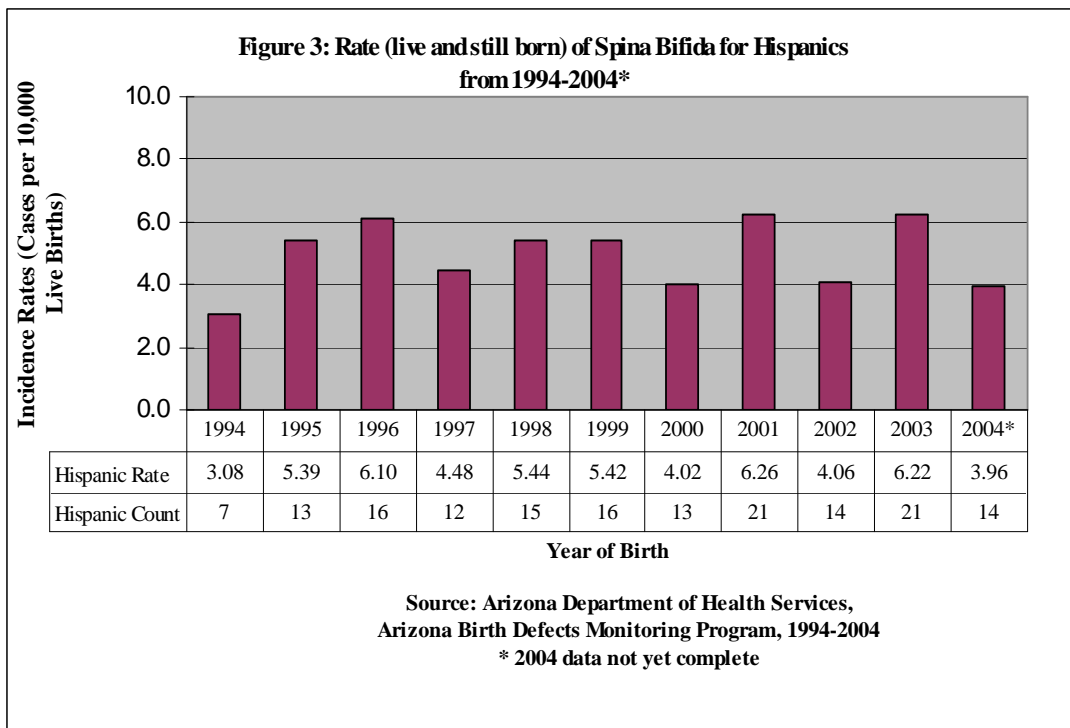
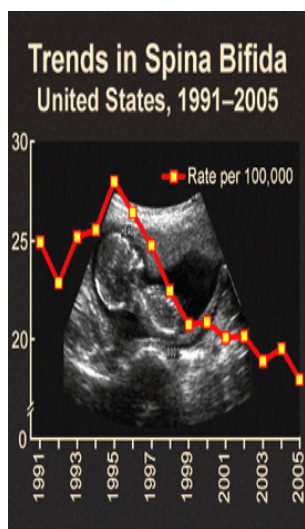
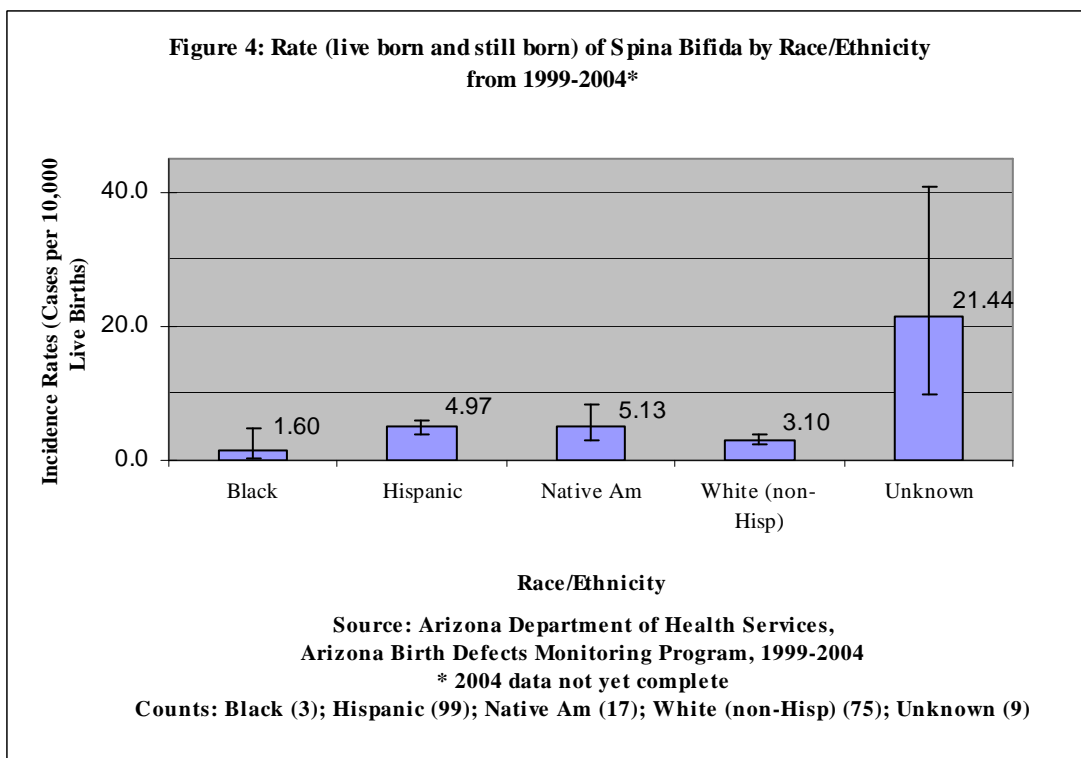


Figure 4: The average rate of Spina Bifida by race/ethnicity for births between 1999 and 2004 includes live born and still born infants.



The national rate of Spina Bifida has decreased since folic acid fortification (graph represents cases ascertained only from certificates of live birth).<sup>9</sup>



## Prevention

Research has demonstrated that primary prevention of birth defects involves folic acid intake. Up to 70% of neural tube defects such as Spina Bifida can be reduced by taking a folic acid supplement.<sup>10</sup> Recognizing that unplanned pregnancies account for 50% of all pregnancies in the United States, the CDC and other organizations recommend that all women of child bearing age take 400 micrograms of folic acid daily.<sup>11</sup> Once women find out they are pregnant, they should increase their folic acid consumption to 600 micrograms. The March of Dimes Foundation notes that most of the prenatal vitamins on the market contain between 800 and 1,000 micrograms of this essential nutrient.<sup>12</sup>

Folic acid is essentially a water-soluble B-vitamin that aids in the production of red blood cells, which women need throughout their pregnancy. Studies have shown that folic acid supplements help women with certain genetic traits, who may not receive adequate amounts of dietary folate.<sup>12</sup> Dietary folate can be obtained in foods such as green, leafy vegetables, beans, orange juice, and cereals.<sup>13</sup>

## Referral Services

The ABDMP is dedicated to identifying children with birth defects so that they can be referred to outreach services.

- The Arizona Early Intervention Program (AzEIP) is a state-mandated outreach program that provides medical services for children up to three years of age. Some benefits of this program include counseling, physical therapy, and developmental screening. Utilizing this service enables children and families to gain the support they need.<sup>14</sup>
- A second state mandated resource is Children's Rehabilitative Services (CRS). This program involves specialty physicians that assist in the treatment of chronic conditions associated with birth defects.<sup>15</sup>
- The Spina Bifida Association (SBA) is a voluntary agency that focuses on serving individuals that live with Spina Bifida. A variety of resources such as research, education, and advocacy issues can be accessed through the SBA.<sup>16</sup>
- The March of Dimes (MOD) is a nonprofit agency that promotes the health of babies by preventing birth defects, prematurity, and infant deaths.<sup>17</sup>

*Folic acid can prevent 70% of neural tube defects.*



Dietary folate and folic acid can ensure the health of mother and child.<sup>13</sup>



Rehabilitation is an important component to treating children with Spina Bifida.<sup>18</sup>

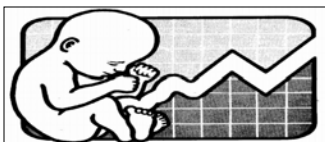
## ABDMP Goals

The Arizona Birth Defects Monitoring Program (ABDMP) is a statewide, population-based, active surveillance program that collects and analyzes information on children with reportable birth defects diagnosed within the first year of life.

### The goals of the ABDMP include :

- To reduce the incidence of birth defects in Arizona from preventable causes.
- To produce accurate statistics regarding the occurrence of birth defects in Arizona.
- To identify, report, and investigate various birth defects trends, high-risk populations, and high risk locations.
- To provide a resource for information about the incidence and epidemiology of birth defects for researchers, health professionals, hospitals, local health agencies, and others with a valid scientific or public health interest.<sup>19</sup>

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**We are on the web!**

**[http://www.azdhs.gov/phs/  
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